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## **Precarity in late life: Rethinking dementia as a ‘frailed’ old age**

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### **Abstract**

Understandings and approaches to ageing that are organized around productivity, success, and active late life have contributed to views of dementia as an unsuccessful, failed or ‘frailed’ old age. Operating through dominant frameworks, socio-cultural constructs and organizational practices, the ‘frailties’ of the body and mind are often used to mark the boundaries of health and illness in late life, and shape responses accordingly. Our concern is that both the taken for granted and the ‘imagined’ can further marginalize persons who occupy the locations of dementia and disablement. This paper analyses the extent to which frailty and dementia are better understood in the context of new forms of insecurity affecting the life course. Drawing on understandings of ‘precarity’, we shift debates on the ‘fourth age’ away from age- or stage-based thinking, into a recognition of shared vulnerability and a responsibility for care. We argue that ‘precarity’ represents ‘new ageing’—in particular as one progresses to the upper extremes of the life course. Pairing our analysis with a consideration of inclusive forms of citizenship, we conclude with a call for a response that is grounded in an acknowledgement of fragility and limitation, and not the denial or distinction from it.

Abstract Word count: 198

### **Precarity in late life: Rethinking dementia as a ‘frail’ old age**

Ideas and assumptions about cognitive impairment, combined with approaches to aging that are organized around productivity, success, and activity, have contributed to views of dementia as an unsuccessful, ‘failed’ or ‘frail’ old age. At the same time, institutional and organizational practices associated with physical and mental frailties are increasingly used to mark the boundaries of health and illness in late life. As such, older persons with physical and/or mental impairments are separated from those deemed healthy, relegated to a period of decrepitude and decline (see Grenier 2012; 2015, Lloyd 2012, Lloyd et al. 2014, Gilleard and Higgs 2010). Policies and frameworks targeted at those in late life tend to focus on either healthy populations (e.g., active or aging), or those in need of care (i.e., ‘the frail’ and/or ‘demented’), thereby sustaining binary distinctions between the third age as a successful lifestyle, and a ‘fourth age’ marked by decline (Gilleard and Higgs 2013, Katz and Calasanti 2015). Even the socio-cultural interpretations have emphasized this age- and stage-based distinction through definitions of the fourth age as an ‘unagentic’ social and cultural space (Gilleard and Higgs 2010). Our concern is that such approaches to late life – both the taken for granted and the ‘imagined’— can further marginalize persons who occupy the locations of dementia and disablement.

Interpretations of dementia as a ‘frail’ and ‘failed’ late life have become highly influential in the context of health and social care practices. The construction of ‘frail’ subjects, itself takes place amidst a larger ‘decline narrative’ (Gullette 1997, 2004), one which is supported by the bio-medicalization of impairment and dementia. Ideas about older people with dementia are also historically situated in pre-welfare state notions applied to being old and frail, as well as modern ideas of dementia as a disease (Chaufan et al. 2011). Concerns have been raised by

researchers about the biomedicalization of memory loss and the extension of this idea into a loss of 'selfhood' (Kontos 2005) and the 'civilized body' (Gilleard and Higgs 2000, Katz and Peters 2008). However, the medicalization of dementia has also raised the status and public attention afforded dementia, sustaining its position as a distinct disease.

Underlying ideas about dementia as impairment are reinforced in the context of the dominance of what has come to be termed 'the successful aging paradigm' (Rowe and Kahn 1997), with dementia and frailty relegated to the 'fourth age'. Although unintended, the emphasis on successful aging, combined with historical and medicalised trajectories of impairment, have crystalized the 'frailties' of impairment and dementia into an 'unsuccessful' or 'failed' late life. Dementia is considered by many to represent a dreaded disease and a 'horrific' end to late life (Katz and Peters 2008, Gilleard and Higgs 2010). This sentiment operates in the public eye, through fund raising campaigns and policy frameworks, often meeting up with discourses about cost and the urgency of response. For example, the opening line of the foreword letter of England's report on Dementia care states "We are facing one of the biggest health challenges ever, a challenge as big as the fights against cancer, heart disease and HIV. Dementia steals lives. It also imposes a huge emotional and financial cost. It is time to fight back" (Department of Health 2013: 2). One response to this has been the establishment of a 'World Dementia Council' together with the setting of a 'global dementia challenge' charged with the goal of finding 'a cure or disease modifying therapy by 2025'<sup>i</sup>

Such understandings of dementia are reinforced in conditions of economic austerity whereby longevity and the increased likelihood of a life with dementia, collide with the loss of rights and citizen entitlements to social welfare. The resulting tension, as this paper argues, is between ideals of independence and the emergence of new forms of vulnerability, or what we shall

term below as ‘precariousness’. The concern of this paper is that current ideas and practices organized around frailty and the discourse of the ‘fourth’ age – both the taken for granted and the ‘imagined’— risk reinforcing unequal power relations in late life, with the potential of further marginalizing persons with dementia. Set against the pervasive power of successful aging, what this paper terms ‘precarity’ is, in many respects, the new ageing— notably so in terms of the upper extremes of the life course. We suggest, therefore, that the concept of precarity be used to reconsider the socio-cultural ideas and practices that operate with regards to dementia, shifting the debates on the ‘fourth age’ away from age- or stage-based thinking, into a consideration of shared processes and experiences of vulnerability that occur over time. Within this frame, precarity can help to draw attention to a deeper problem whereby notions of dementia as a ‘failed’ old age risk being read and interpreted as a ‘failed’ old age.

### **Section I: Frailty, Dementia, and the Discourse of the Fourth Age**

Frailty and dementia have both emerged as conditions which are presented as ‘opposites’ to a ‘healthy’ and ‘active’ later life. In biomedical and health research, frailty has become a major site of research efforts to define the ‘condition’, determine practice indicators, and target health and social care practices to those at ‘risk’ (Fried et al. 2004, Rockwood and Mitnitski 2007, Searle et al. 2008). This is equally the case for dementia, where the diagnosis provides access to specialized services and community-based programs (Brooker 2007). Where health research tends to focus on dementia as a disease or ‘frailty’ as an indicator of risk, socio-cultural perspectives lean toward use of a discourse of the ‘fourth’ age or the discussion of a ‘fourth age space’ that is grounded in ideas about the ‘frailties’ and impairments of late life (Pickard 2014, Lloyd 2015).

The discourse of the ‘fourth age’ as representative of the ‘frailties’ of the body and mind has emerged as a function – or troublesome outcome – of the dominance of a third age lifestyle

characterised by health, personal growth and active engagement (Lloyd 2015). The ‘fourth’ age refers both to an age- or staged- based period of life, as well being a cultural construct that espouses impairment, decline and dependency in late life (see Laslett 1991, Gilleard and Higgs 2000). Whether in practice settings, or the larger socio-cultural sphere, the ‘fourth age’ is an important discursive and symbolic marker of the boundaries between health and impairment, the proximity to death, and by extension, the expectations of late life as a period of disablement and decline (Grenier 2012). It is viewed as a liminal space and an event horizon – a location that holds the negative or less than ideal experiences of aging (Grenier 2012, Gilleard and Higgs 2010). Falling into this space of the ‘fourth age’ therefore, frailty and dementia occupy sites that are laden with associations of physical and cognitive deficits, dependence and burden, pity or weakness (see Grenier 2007, 2012, Pickard 2014).

The marginalisation of those with physical and/or cognitive deficits is reinforced by the lack of agency ascribed to persons deemed to occupy the ‘fourth’ age. The ‘fourth age’ is increasingly described as a complex cultural construct, a ‘social imaginary’ that is unknowable and from which there is no return (Gilleard and Higgs 2010). Gilleard and Higgs (2010: 123) argue in their paper *‘Ageing without Agency’* that: “The fourth age...represents not so much a particular cohort or stage of life but [...] a kind of terminal destination—a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expression and pleasure in later life”. However, an alternative perspective has been put forward by Grenier and Phillipson (2013) who suggest that conditions within the ‘fourth’ age can be said to challenge conventional approaches to the idea of agency. In the case of conditions such as dementia, it is possible to see how agency rather than being ‘compromised’, may simply differ from current interpretations, or be communicated or enacted differently. This

suggestion makes the case for a critical approach to understanding the location of dementia within the life course. Such a perspective is supported by Jaworska (1999), who argues that “the ability to value is independent of the ability to understand the narrative of one's whole life” (124) and “the capacity for autonomy is first and foremost the capacity to espouse values and convictions, whose translation into action may not always be fully within the agent's mastery” (126). Thus, in the context of care services, the task is to value the lives, experiences and convictions of persons with dementia, even in circumstances where what is expressed seems foreign or ‘unknowable’.

Although discourses on the ‘fourth age’ have yet to be fully considered in relation to dementia, approaches organised around selfhood and cultural change represent parallel concerns about dementia as an ‘unagentic’ and ‘failed’ late life. Researchers in dementia studies have stressed the importance of person-centred care and the need to challenge dominant approaches to thinking about the condition (O'Dwyer 2013). George and Whitehouse (2010: 351), among others, have argued: “[...] for the need to challenge the tyranny of the scientifically uncertain and socially stigmatizing AD [Alzheimer Dementia] story to make both cultural understandings and social institutions more responsive, and so that persons with memory challenges and their families may tell their own stories about brain aging rather than succumbing to the generality of a vague, imprecise, and stigmatizing disease label that emphasizes only decline”. Similarly, Kontos (2004) has questioned the idea that cognitive deficiencies leads to a loss of selfhood, and has advocated for arts-based approaches that bridge the differences in communicating our stories (Kontos and Naglie 2007). Yet, current discourses of the ‘fourth’ age run counter to these ideas, reinforcing the view that people with dementia have less agency, with the implication that their lives are both marginal to society and less valued.



To explore this issue, the next section of this paper analyses the extent to which frailty and dementia are better understood in the context of new forms of insecurity that affect the life course, as expressed through ideas associated with the concepts of precariousness and risk.

## **Section II: Precarity as a Means to Reconsider Experiences of Dementia**

The concept of precarity has been used in a number of contexts in order to draw attention to rising insecurities in the context of global economic and social change. In articulating a perspective from critical geography, Waite (2009: 426) refers to precarity as “life worlds characterised by uncertainty and insecurity”, and a concept that implies “both a condition and a possible rallying point for resistance”. Although precarity has been widely used in other fields, in particular with regards to the workforce (Standing 2010), its application to ageing and late life is relatively new. To date the concept has been used to discuss ageing and employment (Bohle et al. 2010), financial insecurity and/or exclusion of older people (Cracium and Flick 2014), disability and citizenship (Knight 2014), and to critique international trends in the G20 (Biggs 2014). In all cases, the use of precarity in gerontology and allied disciplines echo the broad application to issues of exploitation and insecurity in the labour market. The dominance of discourses of success and declining social protection, however, point to the need to consider older people outside the labour force, including those considered ‘frail’ by means of their cognitive and/or physical impairments.

Drawing on precarity to understand the structured and existential vulnerabilities experienced across the life-course and into late life can challenge and potentially reconfigure ideas and practices with regards to physical and cognitive impairment. The insights of researchers such as Standing (2010, 2012) and Butler (2006, 2009, with Athanasiou 2013) are particularly helpful in advancing our reconsideration of dementia as a ‘frail’ and ‘failed’ late life. Although representing different theoretical standpoints, both draw attention to the vulnerabilities in which people are placed. Likewise, they ground their analysis in dependency and the need for change

through a response based on a shared interdependence. Where Standing focuses on a dependency structured by the labour market, Butler emphasizes how responses are based on shared cultural frameworks about the conditions of life, or more specifically, 'what counts as a valued life'. This section provides a brief overview of their work, emphasizing aspects that are most relevant to our consideration of physical and mental frailties and the 'fourth age'.

Uncertainty, insecurity and vulnerability are produced by shifting global, economic, social and cultural relations as well as the choices and decisions made in such contexts. Standing's (2010; 2012) analysis draws attention to the insecurity, unwanted risks, and costly hazards of contemporary life that have resulted from globalization, neo-liberalization, and declining social protection. He focuses primarily on the implications of flexible labour relations and the rollback of public pensions in creating new uncertainties in late life. Drawing older people into precarious work raises issues for social care as well as labour relations. According to Standing (2010), older people can get caught in a 'precarity trap', forced to remain or re-enter the workforce in flexible and lower-income status positions. Older people with limited financial resources may themselves rely upon precarious workers as carers, and family networks may be reduced or drained by means of their own precarity. Standing's (2010) approach also applies to those who provide care services to people with dementia, a high proportion of whom are migrants working in conditions of insecurity and with low rates of pay. As such, his analysis draws attention to how structural inequalities are reinforced through differential 'options' and 'choices' about work and care in later life. Butler's (2009) argument is that we all experience 'precariousness' at different points in our lives, and that 'interdependence' is a feature of the human condition. This perspective is commensurate with that of feminist ethicists concerning the inherent vulnerability and fragility of the human condition. Tronto (1993), for example, argues that although some are more vulnerable than others, 'all humans are extremely vulnerable at some points in their lives'

(Tronto 2011:164). The inevitability of human vulnerability is thus linked to our physical embodiment, which reinforces the point about its universality but also begs the questions – at what points and to what are we made vulnerable? Tronto and others (see for example Sevehuijsen 2003 and Barnes 2012) emphasise that the *political* nature of care ethics, since which human vulnerability gives rise to a need for care in order to ensure human flourishing. However, the primary focus is on the moral imperative to provide care.

Butler's work on precariousness is chiefly concerned with the construction of subjects and the ontological questions of what it means to have a life. According to Butler, "Precarity" is a "politically induced condition in which certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence, and death" (2009: 25). Butler's analysis draws attention to the importance of the differential construction of subjects, and how mutually held frameworks create and sustain particular responses, especially with regards to independence and dependence. Her interpretations of precarity shed light on the politics of ageing, whereby older people can suffer from 'unequal access to material goods, and diminished social networks, resulting in a potential vulnerability to neglect, abuse and violence'.

As such, precariousness raises questions about life and care, and points to concerns about how the construction of a devalued 'fourth age' in the context of declining social protection may place older people at risk of abandonment or ill treatment.

The processes of de-subjection and 'othering' that lead into 'precarity' highlight the potential problems of a devalued 'fourth age'. For Standing (2010), a precarious life characterized by a chronic state of uncertainty and instability can lead to a 'truncated status' where many become 'denizens' as oppose to citizens, defined as lacking at least one group of basic rights (civil, political, economic, social and cultural). Similarly, Butler outlines a shared experience of vulnerability, and

a collective de-humanization that is used to justify devaluation of particular lives. Butler highlights that life, and the decisions made about life, are not selfevident, but constituted by structures of recognition, and discursive power. That is, they are contingent upon mutually-held epistemological and normative frameworks that depict collectives as ‘having or not having a life’, and enacted through decisions and social practices. Such perceptions play a central role in accessing networks of protection and care, and are thus directly relevant to the construction and response to the ‘fourth age’. She illustrates her point through the need for intensive forms of care: “[...] when decisions are made about providing life extending machine support to patients, or extended nursing care to the elderly, they are made, at some level, by considering the quality and conditions of life. To say that life is precarious is to say that the possibility of it being sustained relies fundamentally on social and political conditions, and not only on a postulated internal drive to live" (Butler 2009: 21). A shared schema of ‘fourth age’ ‘dependence’ as a social and cultural burden can thus play a central role in configuring responses and sustaining power organized around a devalued notion of decline.

At the same time, a critical reading of precarity draws our attention beyond the immediate horizon of decisions about care, to recognize and confront the risks of life. Precarity underlines the fact that life is essentially ‘risky’. Unlike previous social divisions organised around class, gender, geography, or ‘racial’ lines, precarity represents a universal form of insecurity, vulnerability, and potential suffering. Standing (2010) argues that contemporary conditions have created a ‘*class-in-the-making*’ (italics in original) — a membership that is open to virtually every member of society whose social, economic and political relationships are destabilized by neoliberal commodification. Butler’s (2009) thinking here is that our lives are, and always have been, defined as a state of precarity, based on an interdependent web of social support and obligations. She argues that: “[...] precariousness implies living socially, that is, the fact that one’s life is always in some sense in the

hands of the other” (2009: 14). This is reinforced by Turner’s (1993: 180) point that individuals may be viewed as ontologically frail rather than autonomous human beings, this arising partly through the effects of ageing and decay, but also because life is inherently risky.

All of these authors draw attention to an inherently shared, but unequally experienced, ‘precariousness’ (also see Tronto 1993). So, while risks or insecurities are part of the human experience, certain locations or lives are more susceptible to the hazards than others, and even more so in a context characterized by precarious work and declining social benefits. Older people increasingly find themselves as linked with precarious work, ever-shrinking social protections and safety nets, and in need of care in later life. Conditions of care shape precarity and underline human inter-relatedness, as can be seen in the accounts of families and carers of people with dementia, who describe a sense of abandonment. Similarly, precarity is evident in the conditions of workers in health and social services where low pay and poor conditions of employment match precisely Standing’s description of the precarious worker (Cangiano *et al* 2009). Realities of ageing and decline combined with age- and care-relations, create a greater risk of precarity, as both structured and experienced.

Finally, the experience of precarity underscores the need for change. Whether drawing on Butler, Standing, or other authors, precarity stresses the need for a response based on interdependence as part of the human condition. Calling for a new progressive vision, Standing (2010: 157) argues: “The precariat’s foremost need is economic security, to give some control over life’s prospects and a sense that shocks and hazards can be managed. This can be achieved only if income security is assured. However, vulnerable groups also need ‘agency’, the collective and individual capacity to represent their interests”. Butler’s emphasis on change is rooted in an ethical response and the relational nature of our existence — our interdependence. Extremely relevant to

the question of dementia and impairment in late life, she states “the question is not whether a given being is living or not, nor whether the being in question has the status of a ‘person’; it is, rather, whether the social conditions of persistence and flourishing are or are not possible” (2009: 20). Here, Butler’s (2009, with Athanasiou 2013) thinking presents a serious challenge to existing discourses of the ‘fourth age’, outlining both that our response to late life should develop from an acknowledgement of fragility and limitation, and not a denial or distinction from it, and that such conditions will not naturally emerge, but need to be fostered.

### **Section III. Shifting the Discussion from the ‘Fourth Age’ as Debility and Decline**

#### **Unhinging Age- and Stage Based Assumptions**

Precarity draws attention to the risks and inequalities across the life course and into late life, underscoring the importance of unburdening ourselves from the age- and stage-based fixations that are implicit in notions of the ‘third’ and ‘fourth’ age. Using precarity to understand late life explicates the construction of the ‘fourth age’ as a location that is distinguished from youth and adulthood, and devalued as a result of impairment and the associated costs of dependency, whether financial or in terms of care/need. It also, however, highlights how ideas are culturally mediated, sustained, and reproduced through institutions and practices. Despite attempts to distinguish aging from a negative period of the life course, the constructs of the third and ‘fourth age’ draw us back to deeply held notions of age as impairment, dependence, and decline. Arguably, the ‘fourth age’ is becoming constructed as old age *per se*. As such, there is a growing realization that the concept of successful aging may operate to the disadvantage of older persons with physical and cognitive impairments. Looking back, it may be the case that the pendulum has returned to the sentiments that Rowe and Kahn (1997), and Laslett (1991), were challenging — the view of ageing as a largely negative experience. We may also see that over time, understandings and approaches to late life

have shifted in line with patterns of mortality, with the burdens of the ‘fourth age’ unequally distributed to those without resources or care networks, and where declining social protection fail to compensate for their needs.

Drawing on interpretations of precarity to understand the ‘fourth age’ accentuates the need for agency and the provision of care as a shared responsibility. When considered in relation to the ‘fourth age’, Butler’s (2009) work suggests that the devalued position of the ‘fourth age’ is created as a period outside normativity, reinforced through cultural norms and practices, and is dependent upon recognition within social structures and systems. Thinking about precarity with regards to late life therefore, helps shift the focus from the negative devaluations of a chronologically situated ‘fourth age’ to considerations of the conditions in which people are living. Chronological age — or any proxy of chronological age such as the third and ‘fourth age’ — and the ways in which we respond to these categories, create and sustain inequalities, many of which are a result of contemporary decisions and priorities about care. The suggestion is therefore, that altering the constitution of subjects, and the responses that take place through social structures and care practices, can create change. Admittedly, 20<sup>th</sup> century patterns of extended longevity have redistributed death from a more equal distribution across the life course to one in which it is overwhelmingly associated with old age. A long life has become so commonly expected – assumed to be a right - that a ‘premature’ death has to be explained. While the cultural impacts of associations between age and death, and similarly dementia and old age, cannot be overlooked, our understandings and responses to late life can. Precarity calls attention to the construction and conditions of vulnerability, including how even the right to a long life is unequally distributed, through for example, differential mortality rates of privileged and disadvantaged groups.

## **Recognizing Vulnerability: The Ethical and Moral Imperative to Care**

Precarity emphasizes the importance of responding to vulnerability in late life as a moral and ethical imperative. The concept of precarity draws attention to the need to question existing care arrangements and the retrenchment of public social services. What makes late life unique with regards to precarity is how the realities of physical and cognitive impairment in late life take on a new dimension as a result of dependence and the finitude that late life represents. This is both in terms of changing needs and the socio-cultural interpretations of dependence. As Lloyd (2015) argues, the ‘fourth age’ shifts the moral imperative to care into a need to be cared for by others. What precarity brings to light is how the need for care takes place in a context where the implications of devalued positions in late life meet up with individualized expectations and discourses of burden. It is precisely how the need for care in late life conflicts with the ‘positive’ views espoused in success-based models, and against a politics of cost containment, that cause the greatest concern with regards to physical and cognitive impairment. In a contemporary context, the relegation of people with dementia to a devalued category of the ‘fourth age’ can all too quickly become a prerequisite for poorly resourced services and threaten responses to care for older people in the ‘fourth age’.

Recognizing precarity and the inherent risks of late life could, however, form the basis for reconfiguring care from a moral and ethical standpoint (see also Gawande 2015). Standing and Butler argue for the construction of conditions that would make life sustainable. Where Standing’s suggestions would mitigate the inequalities that accumulate across the life course, Butler (2009, with Athanasiou 2013) recognizes the roots of suffering as the foundation for an ethical response. According to Butler (2010), the response to precarity should develop from an acknowledgement of fragility and limitation. She articulates that a response capable of improving lives will not naturally occur, but must be created, arguing: “Simply put, life requires support and enabling



conditions in order to be a livable life” (2009: 21). And later, "To sustain life as sustainable requires putting those conditions in place and militating for their renewal and strengthening. Where a life stands no chance of flourishing, there one must attend to ameliorating the negative conditions of life" (23). Butler's point has parallels in philosophical approaches to the ethics of care (Tronto 1993, Sevenhuijsen 1998, Barnes 2012). These would suggest that to the extent that vulnerability is inherent in the human condition, this necessitates the giving and receiving of care in different ways throughout the life course. Perspectives grounded in an ethics of care articulate that the need for care is not confined to 'abnormal' situations, nor is care provision a mere moral and ethical duty. Care is a *political* issue that should be brought out of the private and into the public, and debated, not only in terms of cost and organization, but the potential to respond to need and support human flourishing.

Given the above context, the critique of care as an individual and family responsibility, relegated to private and domestic settings, lends strength to an analysis of precarity in late life (Tronto, 1993, Sevenhuijsen 1998, Barnes 2012). Constructs and practices that confine care to the private realm create and sustain conditions where the complex realities and the need for care can be ignored or overlooked. In the context of this discussion, the devaluing of subjects by means of their cognitive impairment, can serve to reinforce precarity, and deflect attention from both the experiences of living with dementia, and the practices of providing care. In doing so, the associations embedded in the construct of the 'fourth age' may lend strength to programs that provide only minimal public care as a form of compensation for a lack of personal or family resources, rather than care based on the idea that all people 'should be cared for'. With few available care 'choices', constructs of the 'fourth age' which become activated in the current political context, can serve to limit agency as well as reinforce notions that agency is limited in the

‘fourth age’. The foundations for effective communication with people with dementia are thus ignored, and the potential for people living with dementia to shape the conditions within which they live remain unrecognized.

#### **Section IV: Discussion: Citizenship and Vulnerability in Late Life**

The argument of this paper has been that drawing on concepts such as ‘precarity’ can shift ‘fourth age’ discourses and debates away from age- or stage-based thinking that risk reinforcing unequal power relations and further marginalizing older people with physical or cognitive impairments. It does so by rendering visible how current understandings, including those of the ‘fourth age’ as a ‘failed’ late life mask universal suffering, structures of inequality, and processes of precarity. Rooted in the idea of instability and enhanced vulnerability, precarity provides a basis for understanding the particular circumstances that prevail at different points in the life course. It also provides a foundation from which to more closely consider the processes of care and experiences of living with impairment. While rendering visible new forms of aging characterized by precariousness, this leaves open the question of how best to protect people subject to the vulnerabilities associated with late life. Whilst these conditions may be shared across a large section of the population, they are *experienced* by individuals – often living alone and with limited community support. The key issue which arises is how to incorporate the recognition of the vulnerabilities associated with aging and dementia into frameworks which translate into an acceptable response that gives scope for agency (or some variant thereof) and the maintenance of human dignity.

One response is to link the analysis of precarity with an inclusive form of citizenship that challenges the responses to older people with physical and cognitive impairments. The political dimension of the ethic of care can, for example, be linked to the concept of citizenship and the

possibility of changing conventional responses to people with physical and cognitive impairments. To address the application to a wide range of groups, Sevenhuijsen (1998) argues for a view of citizenship that is grounded in an ethics of care, and inclusive of a range of voices. She argues that: “citizenship is not conceptualized exclusively in terms of a liberal rights model but first and foremost as an activity and a normative approach which can lead to a search for the best course of action in public contexts” (148). Such perspectives align with Standing (2010) and Butler’s (2009) views that the conditions for a sustainable life must be fostered. In models of citizenship based on the ethics of care, conflicts of interests are recognised and discussed through processes that ensure that weaker voices are included.

The above argument might be further illustrated through what Delanty (2000) refers to as ‘*cosmopolitan citizenship*’. Challenging a ‘deep moral contradiction at the heart of the modern state’, Linklater (1998: 24) argues that cosmopolitan citizenship is used to “remind citizens of the unfinished moral business of the sovereign state and to draw their attention to the higher ethical aspirations which have yet to be embedded in political life”. In this sense, cosmopolitan citizenship can provide a crucial bridge from our analysis of precarity in late life into pathways for enacting change. A framework that is capable of responding to precarity in late life requires attention to both shared vulnerabilities, and the unequal experiences of such conditions. Linklater (1998) cites Beitz’s view that political communities should widen their ethical horizons until the point is reached where no individual or group interest is systematically excluded from moral consideration. Such an approach challenges the construction of old age as a form of ‘otherness’—a central feature of approaches to dementia and ‘frailty’. It also links with the arguments from the ethics of care, and the need for communication in care practices with older people with dementia. Insisting on the political component of cosmopolitan citizenship, Linklater

(1998: 28) states: “The argument is that, if it is to have real meaning, cosmopolitan citizenship must involve rather more than moral commitments not to exploit the weaknesses of others— more than the ethical resolution to treat all other human beings with care and compassion. It requires political action to build communication communities in which outsiders, and especially the most vulnerable among them, have the power to ‘refuse and renegotiate offers’ and to contest unjust social structures (O’Neill, 1991, as cited in Linklater, 1998, p.28). As such, cosmopolitan citizenship represents an important framework when considering how to move beyond a ‘precarious’ old age.

Both models of citizenship also underscore the importance of inclusion, agency and negotiation that is fostered in part through communication, in this case, even in circumstances where agency is considered to be reduced. A critical analysis drawing on precarity, when combined with an inclusive notion of citizenship, holds the potential to recognize and respond to the needs of older people with dementia. Precarity highlights the severity of the problems that exist for a large number of older people. This leads us to suggest (and fear) that it is ‘precarity’ rather than ‘activity’ and ‘success’, that for particular groups whom have experienced life course disadvantages, is becoming the new model for late life. A careful consideration of the ‘fourth age’ as a form of symbolic exclusion can create the space to reconsider the foundations of constructs and care practices, and ‘what it means to live in a ‘frail state’’. Such considerations will require detailed understandings of the intersecting institutions of health care, social care systems, family relations and subjective meanings—all of which are also shifting over time, and within a politics whereby population aging, and dementia in particular, are considered to represent a costly global burden. The importance of such a political backdrop cannot be overlooked, and it is concepts such

as precarity, in particular, when combined with frameworks such as that of cosmopolitan citizenship, that can help us more carefully consider the impacts on older people.

In some ways, insights from dementia studies have pioneered a reconsideration of late life care. Discussions framed around ‘personhood’, ‘selfhood’ and ‘othering’ have drawn attention to the need to change medical and social practices, particularly the interactions between professionals and people living with dementia, and the reconfiguration of care spaces (see Kontos 2003, George and Whitehouse 2010). Models such as the Eden Alternative or other Dementia-friendly spaces reflect alternative notions of what care ‘should look like’. Such responses have played an important role in reconfiguring dementia, but we also need perspectives that address the socio-cultural and political challenges to interpretations of dementia as a ‘frail’ and ‘failed’ late life. Dementia is by its nature one of the most challenging areas in which to argue against age and stage-based thinking given that it is a chronic, physiologically based condition, leading to death, mostly occurring in old age. Yet, it is a site where constructs of the ‘fourth age’ reinforce negative valuations of dependence as a problem and sustain notions of living with dementia – or other end of life stage conditions—as void of agency and potential.

Dementia and other ‘frailties’ that fall within the ‘fourth age’ signify that mastery over the body cannot be won, that death is inevitable, and simply a question of time (see Lloyd 2000). Such devaluations are, of course, worsened in a context where political notions of dependence interpreted as costly burden can result in non-existent or poor levels of care for older people.

Shifting the focus from constructs that reinforce the negative valuations of age, to a recognized shared vulnerability, acceptance of the limitations of life and death, and shared political responsibility can help to unhinge dementia and impairment from a ‘frail’ and ‘failed’ late life into a foundation from which to develop new types of care relationships. To do so however, relies

on a critical analysis of the constructs, practices, and context within which care for people with dementia takes place, and a linkage with frameworks to guide care practices. Relocating dementia to a more ‘normalized’ life course space however, must not become another rationale for neoliberal care models to relegate care onto families and individuals. Change must also be accompanied by a social and cultural responsibility for care, the prevention of inequalities, the alleviation of suffering, and the opportunity to flourish throughout the life course and into late life. Understandings and discourses of the ‘fourth age’ must, therefore, be repositioned in a space where it is possible to recognize and address vulnerability, inequalities, suffering, as well as the moments of pleasure and joy that can exist in deep old age. We must create structures and programs where ‘care’, and the alleviation of suffering, is both important and possible, and begin to more closely consider and respond to the relationship between cultural, social and biological life, and death.

## **Conclusion**

In conclusion, the contemporary response to dementia in the context of longevity and austerity creates a need to examine the inequalities of late life, the failures of the system with regards to care, and to develop new cultural narratives of deep old age (Phillipson 2015). This will involve a willingness to normalize late life and frailties that occur over time, and recognition that communication and agency may *look different* in later life, and be as much socio-cultural as biological. Turning to an analysis of precarity throughout the life course and in late life outlines the differences that exist, including how late life contains the vulnerabilities of the human condition, the accumulation of structured inequalities, and the socio-cultural assumptions and notions of ‘failure’ that are associated with impairment. Precarity brings makes two contributions to the discussion: first, it moves thinking away from the dominance of individualised age- or stage-based frameworks that are rooted in success, and by consequence, position dementia as a ‘frail old age’. Second, it renders visible, a shared vulnerability, as well as the desire for control, and the

inability, or the lack of political will to address dependency, interdependence and human suffering. Our suggestion is therefore, to pair the analysis of precarity with a response that balances an inclusive form of citizenship, and a recognition and shared responsibility to vulnerability. Only from this point, can we co-create understandings that have the potential to alter current understandings of late life, structures and relations of care, and attempt to alleviate rather than sustain the suffering that may exist in late life. Such approaches would create responses to older people with dementia not because they are pitied or sick, but because they are valued, and because a clearer understanding of their experiences prevails.

## References

- Barnes, M. (2012) *Care in Everyday Life: an ethic of care in practice*. Bristol: The Policy Press.
- Biggs, S. (2014) Precarious ageing versus the policy of indifference: International trends and the G20, *Australian Journal on Ageing*, 33, 4, 226-28.
- Bohle, P., Pitts, C. and Quinlan, M. (2010). Time to call it quits? The safety and health of older workers. *International Journal of Health Services*, 40, 1, 23-41.
- Brooker, D. (2007). *Person-centred dementia care: Making Services Better*. London: Jessica Kingsley Publishers.
- Butler, J. (2006) *Precarious life: The powers of mourning and violence*. London: Verso.
- Butler, J. (2009) *Frames of War: When is life grievable?* London: Verso.
- Butler, J. and Athanasiou, A. (2013) *Dispossession: The performative in the political*. Cambridge: Polity Press.
- Cangiano, A., Shutes, I., Spencer, S. and Leeson, G. (2009) *Migrant Care Workers in Ageing Societies*. Research Findings in the United Kingdom. Oxford University: COMPAS.
- Chaufan, C., Hollister, B., Nazareno, J. and Fox, P. (2011) Medical ideology as a double-edged sword: The politics of cure and care in the making of Alzheimer's disease, *Social Science & Medicine*, 74, 5, 788-95.
- Delanty, G (2000) *Citizenship in a global age: society, culture, politics*. Buckingham: Open University Press

Department of Health (2013). *Dementia: A state of the nation report on dementia care and support in England*. [Online]. Available from: [www.gov.uk](http://www.gov.uk).

Fried, L., Ferrucci, L., Darer, J., Williamson, J. and Anderson, G. (2004) Untangling the concepts of disability, frailty, and comorbidity: Implications for improved targeting and care, *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 59, 3, 255-63.

Gawande, A. (2015) *Being Mortal: Illness, Medicine and What Matters in the End*. London: Profile Books and Wellcome Collection

George, D. and Whitehouse, P. (2010) Dementia and mild cognitive impairment in social and cultural contexts. In Dannefer, D. and Phillipson, C. (eds) *The SAGE handbook of social gerontology*. London: Sage Publications.

Gilleard, C. and Higgs, P. (2000) Aging, Alzheimer's, and the uncivilized body. In Malacrida, C. and Low, J. (eds) *Sociology of the body: A reader*. Don Mills: Oxford University Press

Gilleard, C. and Higgs, P. (2010) Aging without agency: Theorizing the fourth age, *Aging and Mental Health*, 14, 2, 121-8.

Gilleard, C. and Higgs, P. (2013) The fourth age and the concept of a 'social imaginary': A theoretical excursus, *Journal of Aging Studies*, 27, 4, 368-76.

Gullette, M.M. (1997) *Declining to decline: Cultural combat and the politics of the midlife*. Virginia: University of Virginia Press.

Gullette, M.M. (2004) *Aged by culture*. Chicago: University of Chicago Press.

Grenier, A. (2007) Crossing Age and Generational Boundaries: Exploring Intergenerational Research Encounters, *Journal of Social Issues*, 63, 4, 713-27.

Grenier, A. (2012) *Transitions and the lifecourse: Challenging the Constructions of 'growing old'*. Bristol: Policy Press.

Grenier, A. (In Press 2015) *Transitions and time*. In Twigg, J and Martin, W. (eds) *Handbook of Cultural Gerontology*. London: Routledge.

Grenier, A. and Phillipson, C. (2013) Re-thinking agency in later life. In Baars, J., Dhomen, J., Grenier, A. and Phillipson, C. (eds) *Age, meaning and social structure*. Bristol: Policy Press.

Jaworska, A. (1999) Respecting the margins of agency: Alzheimer's patients and the capacity to value, *Philosophy and Public Affairs*, 28, 2, 105-38.

Katz, S. and Calasanti, T. (2015) Critical perspectives on successful aging: does it "appeal more than it illuminates"? *The Gerontologist*, 55, 1, 26-33.

Katz, S. and Peters, K.R. (2008) Enhancing the mind? Memory medicine, dementia, and the aging brain, *Journal of Aging Studies*, 22, 4, 348-55.



- Knight, A. (2014) Disability as vulnerability: Redistributing precariousness in democratic ways, *The Journal of Politics*, 76, 1, 15-26.
- Kontos, P. (2004) Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society*, 24, 6, 829-49.
- Kontos, P. (2005) Embodied selfhood in Alzheimer's disease: Rethinking person-centred care, *Dementia*, 4, 4, 533-70.
- Kontos, P. and Naglie, G. (2007) Tacit knowledge of caring and embodied selfhood, *Sociology of Health and Illness*, 31, 5, 688-704.
- Laslett, P. (1991) *A fresh map of life: The emergence of the third age*. Cambridge: Harvard University Press.
- Linklater, A. (1998) Cosmopolitan citizenship, *Citizenship Studies*, 2, 1, 23-41.
- Lloyd, L. (2000) 'Dying in old age: promoting wellbeing at the end of life'. *Mortality*, 5, 2, 171-88.
- Lloyd, L. (2012) *Health and care in ageing societies*. Bristol: Policy Press.
- Lloyd, L. (2015) The Fourth Age. In Twigg, J. and Martin, W. (Eds) *Handbook of Cultural Gerontology*. London: Routledge. 261-8
- Lloyd, L., Calnan, M., Cameron, A., Seymour, J. and Smith, R. (2014) Identity in the fourth age: perseverance, adaptation and maintaining dignity, *Ageing and Society*, 34, 1, 1-19.
- O'Dwyer, C. (2013) Official conceptualizations of person-centred care: Which person counts? *Journal of Aging Studies*, 27, 3, 233-42.
- Pickard, S. (2014) Frail bodies: Geriatric medicine and the constitution of the fourth age, *Sociology of Health and Illness*, 36, 4, 549-63
- Phillipson, C. (2015) The political economy of longevity: Developing new forms of solidarity for later life, *The Sociological Quarterly*, 56, 1, 80-100.
- Rockwood, K. and Mitnitski, A. (2007) Frailty in relation to the accumulation of deficits, *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 62, 7, 722-7.
- Rowe, J. and Kahn, R. (1997) Successful Aging, *The Gerontologist*, 37, 4, 433-40.
- Searle, S., Mitnitski, A., Gahbauer, E., Gill, T. and Rockwood, K. (2008) A standard procedure for creating a frailty index, *BMC Geriatrics*, 8, 24, 1-10.

Sevenhuijsen, S. (1998) *Citizenship and the ethics of care: Feminist consideration on justice, morality, and politics*. New York: Routledge.

Standing, G. (2010) *The precariat: The new dangerous class*. London: Bloomsbury Press

Standing, G. (2012) The Precariat: From Denizens to Citizens? *Polity*, 44, 4, 588-608.

Tronto, J. (1993) *Moral Boundaries: A political argument for an ethic of care*. New York: Routledge.

Turner, B. (1993) Outline of a theory of human rights, *Sociology*, 27, 2, 489-512.

Waite, L. (2009) A place and space for a critical geography of precarity? *Geography Compass*, 3, 1, 412-33.

<sup>1</sup><http://www.dementiadaily.org.au/dr-dennis-gillings-world-dementia-envoy-a-cure-for-dementia-by-2025/>